

Newborn Screening in France

Organization of the network

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Objective of neonatal screening

- To screen for diseases for which
 - A treatment exists
 - and
 - Will improve the child's condition if initiated early in life

Neonatal Screening

- To reach this goal the French «Social Security» is supporting - and funding - a programme
 - Free of charge for the parents
 - Not mandatory
 - At the **national** level but also at the **regional** level (to be close to the population and to the specialized medical teams in charge of the patients)

Neonatal Screening

Organisation at the National Level

- **Name:**
Association Française Pour le Dépistage et la Prévention des Handicaps de l'enfant
- **Structure :**
President Treasurer - Secretary Council and Committees
- **Role**

Neonatal Screening

Organisation at the National Level

Roles

Decide the strategy

Diseases to be screened , technics to be used , agreement on cut-off

Finances

Establish a budget Collect the funds from the social security and pays the regional-local- structures

Administration

Information

To keep the public informed (leaflets-brochures –web sites)

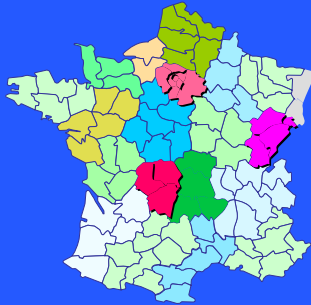
Collect Epidemiological data

Number of Infants Screened and patients diagnosed False + and - Follow-up

Organisation of the Screening

- The Central Structure at the National level supports and controls Regional structures in charge of implementing the screening in the Regions

Regional Organization



- Departement d'outre mer (DOM)
- Reunion Guyane Guadeloupe Martinique St Pierre et Miquelon
- Territoire d'outre mer/Nelle Caledonie Polynesia
- Other

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Quantitative Aspect

In 2004 : 817 388 tests performed

- Great variability

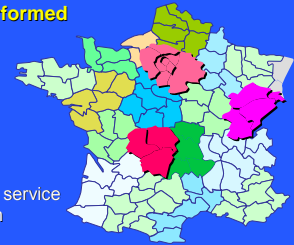
Ile De France : 175 852

Franche Comté : 14 172

Limousin : 7 379

- Advantage : to have a good service at the level of the population

- Disadvantage: Cost



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Roles of the Regions

1 - Implement the strategy defined at the national level

2 - Organize the « working chain »

- Maternity hospitals collect the papers
- Central office register and send the blood spots to labs
- Results back to central office and
- Abnormal/suspect values with ID of parents will be sent to specialised pediatricians who work with the network. They will contact the patients and establish the correct diagnosis and initiate the treatment.
- Central office is informed to fill epidemiological data base

3 - Report to The National office

- Financial and medical data

Diseases Screened

Disease	N N Tested millions	Number of patients	Incidence
PKU	27,2	1573	1/17 292
Congenital Hypothyroidism	20,5	5786	1/3558
Congenital Adrenal hyperplasia	8,8	574	1/15306
Sickle Cell*	1,84	2747	1/669
Cystic Fibrosis	1,9	428	1/4507

* targeted population

Efficacy of Screening

- Close to 100% of the French population
- Age at diagnosis and treatment (days)
 - PKU : 11
 - Congenital Hypothyroidism : 11
 - Adrenal Hyperplasia : 9
 - Cystic Fibrosis : 33
 - Sickle Cell : 59

Conclusion

Well Accepted programme

- By the population : importance of information
- By the medical team in charge of the diagnosis and treatment
- Efficacy
 - Whole population screened
 - Incidence close to expected figures
 - Follow up